

## COMMUNICATION BETWEEN FAMILY AND CHILD: THE MEANINGS OF INTERACTION IN THE SETTING OF CHILDHOOD CANCER<sup>1</sup>

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### ABSTRACT

The objective was to know how the family establishes communication with the child about their illness. This is a qualitative study, involving seven families of children with cancer, from an oncological institution in the interior of the state of Minas Gerais. Symbolic Interactionism was chosen as theoretical reference and Analysis of Thematic Content of Bardin as method. For data collection, a semi-structured interview technique was used. The analysis of the interviews revealed that the family makes a constant selection of words to give meaning to the reality of the child. By intentionally communicating with her, the family re-signifies the context where interactions occur in order to ward off discouraging messages. The results show that the interactions established between family and child are permeated by support. The support that the family offers to the child is recognized in the interactions that it establishes with its peers and with the health professionals. The family unit reveals that health professionals are sensitive to their reality, becoming family support resources in coping with their difficulties.

**Keywords:** Communication. Nursing Oncology. Pediatric Nursing. Family nursing. Family Health.

### INTRODUCTION

Among chronic diseases, childhood cancer is deemed important not only by its high incidence, but also by the psychosocial repercussions in the life of the family unit<sup>(1)</sup>.

The impact of cancer diagnosis and treatment produces emotional trauma, including negative feelings of pain, loneliness, depression, melancholy, withdrawal, hopelessness, sadness, revolt, and exasperation<sup>(2)</sup>. Anxiety triggers crises in the family, an occasion to define and redefine roles within the nucleus<sup>(3)</sup>. The feeling is that the future of the family is compromised by the threat to the child's life. In this context, affectivity is intensified in order to alleviate the suffering of the child in the face of the adversities of treatment<sup>(4)</sup>.

The vulnerability to which the family is exposed increases the risk that their projects will be left on the shelf to meet the child's health needs<sup>(5)</sup>. Thus, it is necessary to strengthen family ties while planning for future interventions to care for the sick child. This interactive process allows the family unit to develop strategies to cope better with the difficult situation. At these times, family members interact, exchange information, find

support, and do everything they can to deal with the disease<sup>(1)</sup>.

Interaction influences the power to communicate, giving the family an opportunity to symbolize all the anguish it has suffered, bringing it together and, with this, improving its ability to cope with the situation and creating a more cooperative attitude towards treatment. The dialogical relationship allows the sharing of experiences and the participation of the family unit in the care process<sup>(6)</sup>.

Thus, communication is an interactive process that allows the family's health needs to be identified and provided, thereby helping members conceptualize their problems, contest them and find possible solutions. Communication can be understood as a set of verbal and non-verbal signals emitted and perceived that expose ideas, making them common in a process of understanding the situation experienced<sup>(7,8)</sup>.

Hence, communication is a tool that allows a relationship, the exchange of ideas and knowledge capable of alleviating family suffering and promoting the best care for the child with cancer. Faced with the challenges of families communicating with their children with cancer, this study aimed to know how the family establishes communication with the child about their disease.

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## METHODOLOGY

This study is part of a Master's thesis<sup>(9)</sup>, approved by the Research Ethics Committee (# 05/2012), that observed the guidelines and norms regulating research involving human beings<sup>(10)</sup>.

This research used a qualitative approach that allowed an understanding of the meanings attributed to the experiences of research subjects and an overall view of the empirical data<sup>(11)</sup>.

Symbolic Interactionism was used as the theoretical reference and Bardin's thematic content analysis as a method to examine data. Symbolic Interactionism is the theoretical reference of human relationships that is employed to understand human behavior from the meanings that individuals comprehend and attribute at any one moment through social interaction<sup>(12)</sup>.

Symbolic Interactionism conceives the human being as active in his experience and under the influence of the definitions generated in his present. Definitions are established, maintained, or transformed by social interactions, both within the individual and with others. That is, individuals create meanings and from them act in the present situation, but under the influence of significant processes of the past and future<sup>(12)</sup>.

Bardin's thematic content analysis is a set of techniques used in the analysis of communication, developed in three stages: pre-analysis (floating reading and hypothesis formulation), exploitation of the material (codification and classification into categories) and treatment of results obtained, and interpretation (reflection process)<sup>(13)</sup>.

The institution selected for the study was the pediatric unit of a Cancer Institute located in a city in the state of Minas Gerais. The service treats children and adolescents with cancer as outpatients and inpatients.

The participants of this study were family members of children with cancer who met the following inclusion criteria: family of school-age children, that is, children aged 6 to 12 years old, undergoing oncological treatment for any type of cancer for at least three months. Family members who suffered the loss of the child

during data collection were excluded from the study.

A semi-structured interview was used to collect empirical data; this instrument enables interactions between two people where the aim of the interviewer is to obtain information from the interviewee<sup>(11)</sup>. Family members were urged to discuss their experience from the guiding question: "Have you told (name of the child) about the disease?"

The interviews took place in the families' homes or in a private room in the healthcare institution, thereby guaranteeing the privacy of the participants. All interviews were recorded, transcribed word for word and analyzed according to the proposed method. All potential participants of thirteen families were contacted for data collection. However, during the study, three children, who met the inclusion criteria, died, two families refused to participate in the study, and one family was excluded from the survey for having participated in the qualification pilot study. Thus, seven families of children with cancer participated in the study giving a total of eight subjects.

To ensure the interviewees' anonymity, names were replaced by the relationship of the family member to the patient and the order in which the interviews were conducted, for example 'Sister 5'.

The empirical data were analyzed comprehensively, seeking to reveal what was behind the manifested contents<sup>(13)</sup>.

## RESULTS AND DISCUSSION

The family's experience in communicating with the child about their illness occurs in a dynamic and integrated process as was revealed by data analysis. This is presented in three major themes: "establishing ill-defined or nebulous communication", "dialoging between truths and secrets" and "finding support beyond words".

The communicational process occurs in an interactional context between family and healthcare professional, nuclear and extended family, as well as family members and their peers; these different interactions influence the way of communicating to the child about their illness, giving dynamicity and integration to the experience.

### **“Establishing ill-defined or nebulous communication”**

When the family discovers the child's illness, interactions and the communication process between social actors occur in an uncertain, vague and self-doubting context. For fear of the unknown, the family does not know how to establish a dialogue with the child about their illness and thus chooses to overlook the disease. It is a nebulously experienced stage through which the family must pass so that it can subsequently establish communications with the child about their conditional.

From the interactionist viewpoint, human actions are differentiated into open actions and disguised actions. An open action is what happens in social interaction, social action, whereas a masked action occurs within the individual before generating an open action<sup>(12)</sup>. In this setting, we seek to reveal the hidden action to motivate an action, that is, to make it possible to understand human actions. The experience modifies family functioning, making it seek a way to rearrange its system. The meaning of the family experience exists in all members, but needs to be conceived in a broader and integral dimension<sup>(14,15)</sup>.

Although the guiding question focused on whether or not the family communicates the diagnosis of cancer to the child, it is evident that the family nucleus needs to return to past situations and events, following the path from the discovery of the diagnosis to the current situation. The family brings the history of their experiences, because it is in this history that the process of communication with the child is embedded; it seems impossible to disassociate experience from the communication itself. The meaning that the family attributes to the current experience is influenced by the experiences of the past that affected the choices and decisions made at the time of communicating the diagnosis.

On being informed of physical changes that are compromising the child's health and observing them, the family starts to investigate. They interact with the biological body of the child to interpret its signals, in search of meanings and definitions about what is happening. In this way, the family looks for health professionals to receive a diagnosis that

explains what the body is manifesting.

She (the child) said: 'Mother, there are two purple spots on my body.' She showed me and I did not want to have lunch. In the afternoon, as she was very dismayed, I said, 'we have to find out why you are like this, I will take you to the doctor's clinic.' (Mother 5)

The process is distressing and usually takes time. Family members find incomplete, dubious and obscure information placing them in a world of uncertainties. They face many obstacles until reaching the diagnosis of cancer: long periods waiting for laboratory results and imaging tests, diagnostic errors and the silence of the health team regarding the signs and symptoms presented by the child.

The family anxiously awaits for confirmation of the diagnosis, information and guidance. An approach with more open dialogue is necessary between the family and health professionals at this stage. Health professionals employ a language little understood by common people, which distresses the parents of the child even more, because it prevents them from understanding the illness of the child.

I would look at the doctors writing mass, mass, mass, but I did not know what it was or what it meant and nobody told me anything. (Mother 3)

It can be seen from empirical data that it is from the moment the diagnosis of childhood cancer is certain that the health team goes directly to the family. This communication happens without the presence of the child.

Receiving the news of childhood cancer causes physical, emotional and social changes in the family unit. Family members believe that they are having a nightmare, they find themselves in a world that brings fear and anguish and they feel guilty for the illness of the child. These reactions happen because the context of cancer inevitably sets bounds for the family. They interpret the news with pain and feelings of sadness, hopelessness and fear of death.

I never thought of cancer. I was listening, but I did not know what it was. (...) you receive the news that your child has cancer. The word cancer, it is ... it is linked to the word death (pause), this is the truth (pause). (...) I did not want to hear the word! (...) I said: '(doctor's name), what are you putting in my head? In my life? What are you

talking about? You're saying that (child's name) is going to ...' (Mother 1)

The diagnosis of cancer brings new responsibilities to the immediate family, which is restructured to provide comfort and support for the child. The period of discovery of the disease allows the family time to review their meanings, redefine them and act in relation to the situation experienced<sup>(16)</sup>. The care of the child involves a range of tasks, including mediating information so that the child cooperates with the treatment<sup>(17)</sup>.

### **“Dialoging between truths and secrets”**

Family members say they do not know how to establish a communication with the child about their illness, because it is a difficult situation to pass through, understand and explain; they do not find words to describe the pain they feel when they see the future of their child is grim.

Parents feel the need to turn to the extended family to share their feelings. By sharing their pain, the family finds ways to cope on the arduous path. They also try to start a decision-making process, that is, there is now a communication of priorities within the family nucleus.

There are continuous decisions in family interactions that involve the future of the child. In this family restructuring to meet the demands of care, the parents face the task of explaining about the illness to the child. This situation is carefully thought over by the parents, who avoid dialogue between themselves and the child as far as possible, seeming to find no words that give meaning to the disease. The impression you have is that when you think about talking to the child about their illness, you are destroying your future. From this perspective, the family initially chooses not to communicate the disease to the child.

Oh boy, it was very difficult! It's very difficult to talk, you have no basis to talk about what's going on! There were days when I came close to talk to her, then I would go back, drink some water, breathe and cry a little. (Father 6)

(...) my family is afraid of the name of the disease, afraid of the problem, so I tried not to talk, I tried to hide it from her. (...) I was afraid people would tease her, so I did not tell her. (Mother 3)

However, in the course of the disease, the family tries to hold back their responses to the feelings of anguish and fear shown by the child

on entering the world of cancer therapy. The family's perception of nonverbal reactions reveals that the child interprets the hospital environment as a threat to their physical and emotional completeness. In this context, the child questions the family about the change in routine and, consequently, their health condition.

Faced with this questioning and the difficulties of cancer therapy, the family unit decides to establish a communication with the child about their disease. For this, it adopts a protectionist language. This communication process is permeated by a constant selection of words that do not give the child the meaning of their illness and, consequently, of death. The desire of the family unit is to transmit messages of hope that encourage the child to confront the situation.

(...) As (child's name) was already frequenting the hospital, I said she was going because she was sick, she had that little lump on her neck. Then she knew she had to go to the hospital for the lump that was on her neck, but she did not understand that it was cancer. (Mother 7)

(...) I said the tumor was a lump in her leg, it was evil, that it was bad and so it had to be removed. (...) I said it might be genetic: 'Daughter, this may have come from grandma and great-grandma, who died with this disease and you inherited it.' I told her this could be in the family. (Father 6)

Language allows us to imagine and perceive a reality beyond what is concrete. Through language, we can establish objects: God, good and evil, truth, freedom and other abstract objects that are part of our existence. Human beings are users of symbols and capable of creating an abstract world, they can imagine goals, ideals and values, and this abstract reality becomes an important motivating factor of human behavior<sup>(12)</sup>.

The family's anxiety for communication with the child is intertwined with the meaning it attributes to the disease and its consequences. From this perspective, the family intentionally communicates with the child to convey support and hope.

Past experiences are present in the communication with the child because the family believes that the meaning of cancer marks people in unwanted and unexpected ways and fears that the child will live with these marks. Thus, the family unit constitutes a support network to face the chronicity of the circumstances.

The network of relationships established by the child's family enables support resources offered to it to fluctuate through these connections, assisting in communication with the child, as well as in coping with the disease<sup>(18)</sup>.

### **"Finding support beyond words"**

In the process of living with the disease, the family is a source of support for the child, constantly seeking strategies that keep negative feelings away from their child to prevent them from having to face the disease<sup>(19)</sup>. Members of the family put themselves in the shoes of the child trying to understand the difficulties of experiencing chronicity. They adapt games to the reality of the child so that the hospitalization and the limitations of the disease are overcome without too much suffering and restrictions.

(...) She (the child) loves to play games, so I taught (child's name) to play a little game to get through hers. (...) There were days she said: 'Mother, let's play singing?' She loves to sing and I would say 'you sing and mum will listen because I suck at singing'. (...) I bought makeup, headscarves and hats, because she is very vain. (Mother 2)

To assume the role of the other is to understand things through different points of view, in this case trying to understand from the child's point of view what it is like to go through these situations<sup>(12)</sup>. The family believes that the physical transformations resulting from the treatment of cancer mark the child in an undesirable way, because society shows prejudice in respect to this disease. That is why the mother changes the child's clothing to announce to others her new identity. She does this to prevent the child from suffering any preconception against her illness.

The social network built by the family has much to contribute to improving the quality of life of the child. In one study that aimed to investigate the influence of the social network in coping with the disease, adolescents reported that when they felt supported and included in their social environment, they felt more prepared and stronger to face the adversities of the disease<sup>(5)</sup>. The verbalized words and the gestures demonstrated by parents to their

children are a source of support to face the innumerable difficulties of treatment and the repercussions that this has in their family life. Thus, the family has the ability to interrelate with others in order to support and care for the child with cancer<sup>(20)</sup>.

Considered an event that builds the way of life that is formed within social interactions, playful communication is the resource elicited by the family in the dialogue with the child in order to soften the information content. This communicational strategy enables the family to clarify the child's doubts about their illness with messages of encouragement that enable them to cope with the situation they are living through. Parents, by using this symbol, hope to provide an optimistic version of reality, encouraging the child to seek the best.

The interactions established in the disease process are permeated by positive communication that assists on the arduous path. Messages of hope of overcoming the problems are employed to help the child to face the situation. Furthermore, the family believes that an encouraging communication reduces the suffering experienced by their child.

In this context, the interactional process between family and child is the result of lived experiences. They fight to believe in a different, better future in order to overcome the current situation. Thus, the attitudes and words uttered by the family unit, trying to convey to the child hope of overcoming the disease, are the fruit of their conception of the future.

### **FINAL CONSIDERATIONS**

Knowing how the family establishes communication with the child about their illness is fundamental, as communication is an essential tool in the practice of care. The interactional experience of the families participating in this study is characterized by meanings attributed to previous experiences related to the current situation; these are taken into account when communicating with the child.

The family is attentive and concerned about what it communicates to the child. Thus, it seeks to interact in order to convey messages of encouragement and hope to pass through the difficult moment.

The family mobilizes, restructures, and creates coping strategies. For this, it adapts its language to meet the child's need for information, trying not to give the meaning of the disease or any possibility of death.

At all times in the communicational process, the family unit constitutes an informational and emotional support network, orienting the child on the benefits of being submitted to treatment. Family members believe that, with their commitment and dedication, they will achieve the full development they want so much.

Family support for the child is recognized in the interactions established with peers and health professionals. The family unit shows that these professionals are sensitive to their reality as they offer support to the family in the face of their difficulties.

Although this study presents limitations, such as the small number of participants, which prevents a generalization of the results, its finalization allows the identification of gaps in knowledge in the nursing setting. It points out the need for further research to better understand

the meaning of the following demands: communication between family and children aged from 0 to 6 years; communication between family, adolescents and young people; and communication in cases of relapse, since this is a situation that accentuates and revives feelings of fear and anxiety. It is also important to highlight the issue of the management of the preconception involved in the communication between family and child in respect to this moment of vulnerability.

It is evident that healthcare professionals need to strive to provide care that promotes development, growth and rehabilitation. This task needs to be performed quietly and effectively so that it benefits the family unit. The nursing team needs to invest in improving communication processes with the family.

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## COMUNICAÇÃO ENTRE FAMÍLIA E CRIANÇA: SIGNIFICADOS DA INTERAÇÃO EM SITUAÇÃO DE CÂNCER INFANTIL

### RESUMO

O objetivo do estudo foi conhecer como a família estabelece a comunicação com a criança sobre sua doença. Trata-se de um estudo de abordagem qualitativa, da qual participaram sete famílias de criança com câncer, de uma instituição oncológica do interior do estado de Minas Gerais. Optou-se pelo Interacionismo Simbólico como referencial teórico e Análise de Conteúdo Temática de Bardin como método. Para a coleta de dados foi utilizada técnica da entrevista semiestruturada. A análise das entrevistas revelou que a família faz uma constante seleção de palavras para dar significado à realidade da criança. Comunicando-se intencionalmente com ela, a família ressignifica o contexto onde as interações ocorrem a fim de afastar mensagens desanimadoras. Os resultados mostram que as interações estabelecidas entre família e criança são permeadas de apoio. O apoio que a família oferta à criança é reconhecido nas interações que estabelece com seus pares e com os profissionais de saúde. A unidade familiar revela que os profissionais de saúde estão sensíveis a sua realidade, tornando-se recursos de suporte para a família no enfrentamento de suas dificuldades.

**Palavras-chave:** Comunicação. Enfermagem Oncológica. Enfermagem Pediátrica. Enfermagem familiar. Saúde da Família.

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## COMUNICACIÓN ENTRE FAMILIA Y NIÑO: SIGNIFICADOS DE LA INTERACCIÓN EN SITUACIÓN DE CÁNCER INFANTIL

### RESUMEN

Conocer cómo la familia establece la comunicación con el niño sobre su enfermedad. Se trata de un estudio de enfoque cualitativo, que tuvo la participación de siete familias de niño con cáncer, de una institución oncológica del interior del estado de Minas Gerais-Brasil. Se optó por el Interaccionismo Simbólico como referencial teórico y el Análisis de Contenido Temático de Bardin como método. Para la recolección de datos fue utilizada la técnica de la entrevista semiestruturada. El análisis de las entrevistas reveló que la familia hace una constante selección de palabras para dar significado a la realidad del niño. Comunicándose intencionalmente con él, la familia replantea el contexto donde las interacciones ocurren a fin de alejar mensajes desalentadores. **Conclusión:** Los resultados muestran que las interacciones establecidas entre familia y niño son basadas de apoyo. Este apoyo ofrecido al niño es reconocido en las interacciones que establece con sus pares y con los profesionales de salud. La unidad familiar revela que los profesionales de salud están sensibles a su realidad, volviéndose en recursos de soporte para la familia en el enfrentamiento de sus dificultades.

**Palabras clave:** Comunicación. Enfermería Oncológica. Enfermería Pediátrica. Enfermería familiar. Salud de la Familia.

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